

A reflection on: Breitbart W (2020). Life and death in the age of COVID-19. *Palliative and Supportive Care* 18, 252–253

Letter to the Editor

Cite this article: Neto IG (2021). A reflection on: Breitbart W (2020). Life and death in the age of COVID-19. *Palliative and Supportive Care* 18, 252–253. *Palliative and Supportive Care* 19, 265–266. <https://doi.org/10.1017/S1478951520001376>


Received: 11 November 2020

Revised: 8 December 2020

Accepted: 27 December 2020

Author for correspondence:

Isabel Galriça Neto, Palliative Care Unit, Hospital da Luz-Lisboa, Lisbon University Medical School, Catholic University, Lisbon, Portugal. E-mail: isaneto@netcabo.pt

Isabel Galriça Neto, M.Sc. 

Palliative Care Unit, Hospital da Luz-Lisboa, Lisbon University Medical School, Catholic University, Lisboa, Portugal

Dear Editor

“This COVID-19 pandemic is forcing us to ‘Stare at the Sun’ too long,” as Breitbart (2020) writes in a recent excellent article, where he also speaks about the possibility of transforming the future. Due to the COVID-19 pandemic, we have witnessed significant changes in the way various health services operate, and Palliative Care (PC) is no exception. As a medical director in a Portuguese PC unit in a large tertiary hospital, and after reading that text, I reflect on the impact and changes that have occurred, challenges and opportunities that we have faced in recent months and in the near future.

PC, which deals with various dimensions of people’s suffering, of all ages, in serious, life-threatening illness, or in advanced, incurable diseases, is essential to thousands of Portuguese people. PC includes care and support for families, which stretches from support to informal carers to grief period. PC is focused on symptom control but extends far beyond this to essential existential, social, cultural, spiritual, and religious issues, to making complex ethical decisions and advanced care planning. The relationship with the patient is central to good PC (Twycross, 2020).

Emphasis has been placed in technical demands present during this pandemic: the need for ventilators, special equipment, and trained staff, but much less has been said of the thousands of non-COVID patients, suffering from chronic illnesses, who have been neglected from this shift in focus. We argue that this cannot be justified solely by a focus on the need for survival, but that attention must be paid to the importance of the continued need for quality of life, dignity, and relief of suffering of our patients. PC could be recognized in this pandemic, as an asset, in a consulting capacity for patients with SARS CoV2 infection who require symptom optimization, for those who require specialist PC, but above all, for maintaining the care and treatment of non-COVID PC patients (Abbot et al., 2020; Fadul et al., 2020; Knights et al., 2020), which represent a much larger group of people.

PC interventions are needed more than ever. Unfortunately, in our country, this has not been the case but rather the care we provide has been significantly compromised, particularly by the displacement of human resources to other areas, further intensifying the deficiency in specialist PC already obvious in this area, previously.

As a result of the imposition of social isolation and restriction of contacts, the pandemic has translated into a period of extreme loneliness for vulnerable patients, many in their final weeks of life. Furthermore, the doctor–patient relationship has been fundamentally affected, with the mandatory use of personal protective equipment: the use of mask hides our facial expression and affects our communication, both verbal and non-verbal (Back et al., 2020; Marra et al., 2020), so essential for PC. Communication is sometimes barely understandable, let alone empathic, genuine, and caring. This physical distance, advocated for our survival, limits the possibility of spontaneous, reactive affectionate contact, a hug, or holding of a hand, which may be necessary in support of a patient at their most dire time of need.

Many patients, even if severely ill with chronic life-threatening illnesses, will maintain the capacity for verbal communication and interaction until quite close to their death, these patients might spend these last moments of their lives alone, isolated from those who are dearest to them, with complex psycho-social and medical needs. We don’t deny the extraordinary period of time we are living and the necessary means that have been used to fight it, but we cannot forget or negate the obvious consequences of the isolation previously described (Chapman et al., 2020). We believe that the resulting anguish, anxiety, fear, and depression will negatively affect the preservation of dignity. The suffering present in dealing with the complexity of end-of-life issues (fear of death, feeling vulnerable, self-esteem, and dignity self-concept) (Chochinov et al., 2020; Patneau and Kett, 2020) will be augmented by the social impositions of this COVID-19 pandemic. Symptom control will become more complex and require more supervision and focus from a specialist PC team.

In PC, the family is, under normal circumstances, provider and receiver of care. The family also suffers from consequences arising from isolation (Marra et al., 2020), with less proximity to their family members and their medical team, especially during particularly emotionally

demanding times. They wonder whether their family member is comfortable, if they call, will they be heard... This leads to feelings of anxiety, anguish, sometimes even guilt, anger, and frustration.

Direct support for family members and carers is also more limited, communication by other means to ensure distance is very different in nature, to that which is given in person. This reduction in quality or quantity of support given, may be translated into the greater frequency of pathological grief (Back et al., 2020; Chochinov et al., 2020; Marra et al., 2020).

All these issues and changes contribute to increase the pressure which is placed upon healthcare professionals, who themselves are living in a unique situation, with a great demand upon their services, the discomfort of using personal protective equipment, greater number of shifts, frequent exposure to positive cases, and potential fear of infection themselves. This may lead to great tension, possible burnout, and a feeling of duty not fulfilled.

We point out that, in PC, the consequences of COVID-19 will not only be of an instrumental or organizational nature but can compromise the very essence and nature of PC (Chapman et al., 2020; Twycross, 2020). This time calls for flexibility and adaptation, but the nature of PC should not be forgotten, a service which delivers interventions of great complexity. How will PC adapt, to a pandemic, when there isn't an endpoint in sight?

This healthcare crisis may present hidden opportunities, particularly in expanding PC principles to those non-specialist professionals. This may be an opportunity, if resources allow, for PC teams to reach out to colleagues in other specialties and expand the PC approach models, focusing on the importance of teamwork and highlighting relief of suffering as a genuine goal of care, rather than survival alone (Abbot et al., 2020; Fadul et al., 2020). Taking this opportunity to disseminate good symptom control protocols and draw attention to the significance of the relationship with our patients, offering training in communication skills and in advance care planning (Back et al., 2020; Chochinov et al., 2020; Marra et al., 2020; Patneude and Kett, 2020).

Despite this crisis, health professionals should not lose their capacity for empathy (Back et al., 2020; Patneude and Kett, 2020). It is essential to be attuned to patients' emotions, validate them and provide guidance for dealing with them. Compassion is essential, a relationship with patients which is based on respect, attention to details, and validation of emotions, should be favored. The use of "remote" communication strategies, through the use of new technologies (videoconferences, video calls, etc.) has proven to be very useful at this stage — and probably will continue to be so in the future — but it cannot replace face-to-face interventions altogether.

In a crisis situation like the one we are experiencing, one of the biggest challenges, encountered often in clinical practice, is the ethical challenge of attempting to reconcile individual needs and values of a patient with the need to allocate resources with the interests of the population instead (Abbot et al., 2020; Chapman et al., 2020). Some patient's choices may be limited, and the professional should explain the reasons for these

limitations, reinforcing other viable options, using teamwork, drawing on creativity and competence. Domiciliary and home-based care should be favored in this context (Fadul et al., 2020).

This daily and frequent exposure to death, in various circumstances, may contribute to, as health professionals, a greater awareness of our own mortality and self-care and burnout prevention is essential (Back et al., 2020). For society in general, it can represent an alert to the need to enable a health care and social support system that better deals with those who are not cured, the elderly, those with chronic conditions as well as the need for a timely discussion of patient wishes and advanced care directives.

"The recognition that palliative care is an important, equal, and in some situations, favourable alternative to resource-intensive care when resources are scarce" is paramount and rings true in this pandemic situation (Chapman et al., 2020). We are undoubtedly experiencing a complex phase, of enormous demand — for patients, family members, and health professionals alike — and of enormous potential for transformation (Breitbart, 2020). PC is expected to be up to the task, accessible to anyone in any context, so as not to leave anyone behind, let alone the most vulnerable and those who are suffering. This is our challenge and our commitment.

Acknowledgement. We thank Dr.^a Rita Vieira Alves for the review of the translation.

Conflict of interest. No competing financial interests exist for the author; no conflicts of interest.

References

- Abbot J, Johnson D and Wynia M (2020) Ensuring adequate palliative and hospice care during COVID-19 surges. *JAMA* 324(14), 1393–1394.
- Back A, Tulsky JA and Arnold R (2020) Communication skills in the age of COVID-19. *Annals of Internal Medicine* 172(11) 759–760.
- Breitbart W (2020) Life and death in the age of COVID-19. *Palliative and Supportive Care* 18(3), 252–253.
- Chapman M, Russell B and Philip J (2020) Systems of care in crisis: The changing nature of palliative care during COVID-19. *Bioethical Inquiry* 17(4), 761–765.
- Chochinov H, Bolton J, Sareen J, et al. (2020) And dignity in the time of the COVID-19 pandemic. *Journal of Palliative Medicine* 23(10), 1294–1295.
- Fadul N, Elsayem AF and Bruera E (2020) Integration of palliative care into COVID-19 planning. *BMJ Supportive & Palliative Care*, doi:10.1136/bmjspcare-2020-002364, 1–5.
- Knights D, Knights F and Lawrie I (2020) Upside down solutions: Palliative care and COVID-19. *BMJ Supportive & Palliative Care*, doi:10.1136/bmjspcare-2020-002385, 1–5.
- Marra A, Buonanno P, Vargas M, et al. (2020) How COVID-19 pandemic changed our communication with families: Losing nonverbal cues. *Critical Care* 24, 297.
- Patneude A and Kett J (2020) Cultural responsiveness and palliative care during the COVID-19 pandemic. *Palliative Medicine Reports* 1(1), 171–173.
- Twycross R (2020) Palliative care: What, who, when, how? *World Medical Journal* 66(2), 25–28.